

**Patient perspectives on diagnosis and management of hidradenitis suppurativa: A web-based survey**



*To the Editor:* Hidradenitis suppurativa (HS) is a chronic, recurrent inflammatory disease characterized by inflammatory nodules, abscesses, sinus tracts, and scarring.<sup>1,2</sup> HS is associated with high physical and psychological burden and reduced quality of life.<sup>3,4</sup> HS diagnostic delays and management challenges are widely acknowledged; however, limited data are available on patient perspectives through HS diagnosis and treatment.<sup>5</sup> This survey study describes patient experiences from symptom onset to treatment initiation and disease management.

This prospective web-based survey study was conducted between December 15, 2020, and January 31, 2021. Of 50 patients with HS invited to complete the 46-question survey, 47 completed it for a response rate of 94%; all provided written informed consent prior to participating. Ethics review and data privacy approvals were obtained through a centralized institutional review board. Patients were questioned on demographics, disease characteristics, journey to care, and disease management. Descriptive analyses were conducted by Guidehouse using SAS statistical software or Microsoft Excel.

Patient demographics and clinical characteristics were comparable to those previously described for HS populations in the United States. One-third of patients (31.9%) sought medical help only when symptoms became unbearable (Supplementary Table, available via Mendeley at <https://data.mendeley.com/datasets/ydk2byc832/1>). Most patients (70.2%) self-treated with nonprescription therapies before seeking medical help (Table I). One-third of patients were referred to a dermatologist; of these, 60% reported that their referral process was “very/somewhat difficult.” Patients experienced substantial diagnostic delays, and 40.4% of patients waited >1 year from diagnosis to the first prescribed treatment. HS symptoms had a major impact on patients’ daily activities, and 57.4% reported feeling embarrassed, anxious/nervous, or down/depressed about their disease.

Patients reported mixed feelings upon receiving their diagnosis, with 51% feeling relieved to have a

**Table I.** Patient-reported experiences from symptom onset through HS diagnosis and management

Characteristic (N = 47)*	Patients with HS, n (%)
Tried nonprescription therapies before seeking medical help <sup>†</sup>	33 (70.2)
Referral to dermatologist	15 (31.9)
Patient experience with the referral process, n = 15 <sup>‡</sup>	
“Very difficult”	7 (46.7)
“Somewhat difficult”	2 (13.3)
“Neutral”	5 (33.3)
“Somewhat easy”	1 (6.7)
Time from symptom onset to diagnosis	
<1 y	5 (10.6)
1-5 y	13 (27.7)
5-10 y	9 (19.1)
>10 y	20 (42.6)
Time from diagnosis to the first prescribed treatment	
Before diagnosis <sup>§</sup>	1 (2.1)
Immediately	15 (31.9)
<1 mo	7 (14.9)
<1 y	5 (10.6)
1-5 y	10 (21.3)
5-10 y	4 (8.5)
>10 y	5 (10.6)
Time from the first treatment to biologic initiation, n = 22	
1-6 mo	6 (27.3)
7-11 mo	2 (9.1)
1-2 y	5 (22.7)
>2 y	9 (40.9)
Patient-reported biggest disadvantages of biologic treatment, n = 22 <sup>  </sup>	
Satisfaction with disease control	10 (45.5)
Side effects	9 (40.9)
Expensive cost	7 (31.8)
Forget to take treatment	3 (13.6)
Does not work as fast as desired	3 (13.6)
Other	2 (9.1)
Does not like needles/injections	1 (4.5)
Too much time needed to take it/ travel to treatment center	1 (4.5)
Patient concerns that their current treatment will stop working	
“Very worried”	17 (36.2)
“Somewhat worried”	8 (17.0)
“Little worried”	11 (23.4)
“Not worried”	11 (23.4)

Continued

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**Table I.** Cont'd

Characteristic (N = 47)*	Patients with HS, n (%)
"Extreme/very much" feelings reported by patients about HS	
"Embarrassed"	27 (57.4)
"Nervous/anxious"	27 (57.4)
"Down/depressed"	25 (53.2)

HS, Hidradenitis suppurativa.

\*N = 47 unless otherwise specified.

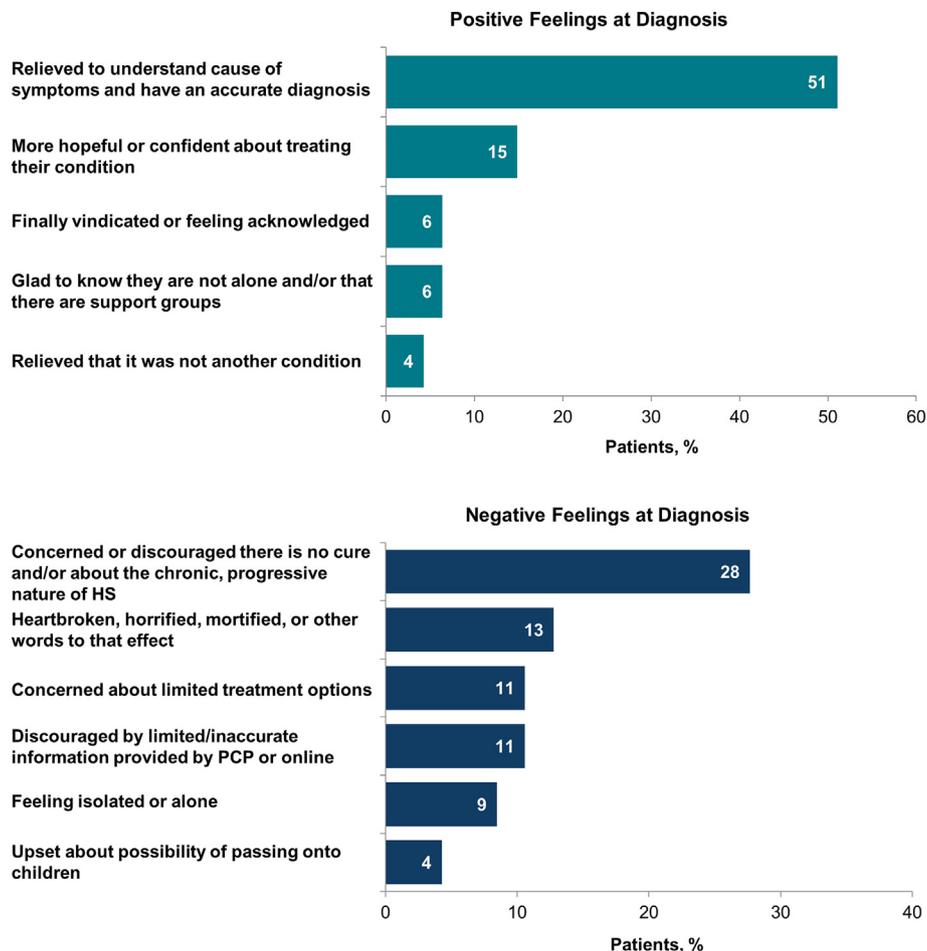
†Nonprescription therapies most frequently mentioned by patients included pain killers (eg, acetaminophen, ibuprofen), epsom salt, black salve, and antibacterial washes and ointments.

‡Only includes patients who had been referred to a dermatologist. No patients reported that the referral process was "very easy."

§Received pharmacological treatment before diagnosis.

||Patients could select more than 1 response; other included "quarterly blood work and increased chance of TB/infections" and "adalimumab no longer worked, taken more than once."

diagnosis for their symptoms and 28% feeling discouraged about the chronic/progressive nature of HS (Fig 1). Only 36% of patients reported that their disease was well managed by their current physician. The majority (74%) reported they were never prompted to talk about HS with a mental health professional, and 40% were never counseled on lifestyle modifications (Supplementary Fig 1, available via Mendeley at <https://data.mendeley.com/datasets/ydk2byc832/1>). Of the 22 patients (46.8%) who were prescribed biologics, 66% reported biologics as the most helpful treatment class (Supplementary Fig 2, available via Mendeley at <https://data.mendeley.com/datasets/ydk2byc832/1>). Over one-half of patients (53.2%) expressed that they were very/somewhat worried that their current HS treatment would stop working (Table D). Furthermore, the top patient-reported disadvantages



**Fig 1.** Patient reactions to receiving HS diagnosis (N = 47). HS, Hidradenitis suppurativa; PCP, primary care provider.

of biologics included dissatisfaction with disease control (45.5%), side effects (40.9%), and expensive cost (31.8%) (Table D). These findings are limited in their generalizability due to the modest sample size, the uncontrolled setting, and the localized geography.

Patient perspectives substantiated major diagnosis and treatment delays, mixed emotions upon receiving the diagnosis of HS, and perceived poor disease management. Strategies to help improve HS diagnosis and delivery of care may include public awareness campaigns, transparent and compassionate patient–physician interactions about HS, increased education about treatment options, and development of novel accessible and affordable therapeutics with durable efficacy. Multidisciplinary care and increased patient and provider awareness are needed to address gaps in delivering comprehensive and timely HS care with improved patient satisfaction.

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*Patient consent:* Patients provided written informed consent for use of medical information to be published in print and online prior to

*participating, and all informed consent forms are on the file with the physicians. No patient photographs were collected/used for this study.*

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#### Conflicts of interest

J.L. Hsiao is on the board of directors for the Hidradenitis Suppurativa Foundation (HSF) and has served as an advisor for Boehringer Ingelheim, Novartis, and UCB and as a speaker and advisor for AbbVie. V.Y. Shi is on the board of directors for the HSF; serves as an advisor for the National Eczema Association; is a stock shareholder of Learn Health; and has served as an advisory board member, investigator, speaker, and/or received research funding from Sanofi Genzyme, Regeneron, AbbVie, Eli Lilly, Novartis, SUN Pharma, LEO Pharma, Pfizer, Incyte, Boehringer Ingelheim, Aristeia Therapeutics, Menlo Therapeutics, Dermira, Burt's Bees, Galderma, Kiniksa, UCB, Target-PharmaSolutions, Altus Lab/cQuell, MYOR, Polyfins Technology, GpSkin, and Skin Actives Scientific. E. Muscianisi and J. Darcy are employees of Novartis Pharmaceuticals Corporation. E. Nguyen is an employee of Novartis Gene Therapies. J.S. Kirby is on the board of directors for the HSF and has served as an advisory board member, investigator, speaker, and/or consultant for AbbVie, ChemoCentryx, CSL Behring, DermTech, InflaRx, Incyte, Novartis, Janssen, Pfizer, and UCB.

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